DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Disease Control and Prevention

[60Day-22-22IV; Docket No. CDC-2022-0112]

Proposed Data Collection Submitted for Public Comment and Recommendations

AGENCY: Centers for Disease Control and Prevention (CDC), Department of Health and Human Services (HHS).

ACTION: Notice with comment period.

SUMMARY: The Centers for Disease Control and Prevention (CDC), as part of its continuing effort to reduce public burden and maximize the utility of government information, invites the general public and other federal agencies the opportunity to comment on a proposed information collection, as required by the Paperwork Reduction Act of 1995. This notice invites comment on a proposed information collection project titled The Muscular Dystrophy Surveillance, Tracking, and Research Network (MD STAR*net*) Muscular Dystrophy Questionnaire. The purpose of the proposed study is to describe the epidemiology of COVID-19 and flu and the experience with pain, fatigue, pregnancy, and infertility for adults living with muscular dystrophy (MD) who are identified through MD STAR*net*. Information will be used to develop interventions that improve the lives of people with MD and their families.

DATES: CDC must receive written comments on or before [INSERT DATE 60 DAYS AFTER PUBLICATION DATE IN THE FEDERAL REGISTER].

ADDRESSES: You may submit comments, identified by Docket No. CDC-2022-0112 by either of the following methods:

- Federal eRulemaking Portal: www.regulations.gov. Follow the instructions for submitting comments.
- Mail: Jeffrey M. Zirger, Information Collection Review Office, Centers for Disease Control and Prevention, 1600 Clifton Road, NE, MS H21-8, Atlanta, Georgia 30329.

Instructions: All submissions received must include the agency name and Docket Number. CDC will post, without change, all relevant comments to www.regulations.gov.

Please note: Submit all comments through the Federal eRulemaking portal (www.regulations.gov) or by U.S. mail to the address listed above.

FOR FURTHER INFORMATION CONTACT: To request more information on the proposed project or to obtain a copy of the information collection plan and instruments, contact Jeffrey M. Zirger, Information Collection Review Office, Centers for Disease Control and Prevention, 1600 Clifton Road, NE, MS H21-8, Atlanta, Georgia 30329; Telephone: 404-639-7118; E-mail: omb@cdc.gov.

SUPPLEMENTARY INFORMATION: Under the Paperwork Reduction Act of 1995 (PRA) (44 U.S.C. 3501-3520), federal agencies must obtain approval from the Office of Management and Budget (OMB) for each collection of information they conduct or sponsor. In addition, the PRA also requires federal agencies to provide a 60-day notice in the *Federal Register* concerning each proposed

collection of information, including each new proposed collection, each proposed extension of existing collection of information, and each reinstatement of previously approved information collection before submitting the collection to the OMB for approval. To comply with this requirement, we are publishing this notice of a proposed data collection as described below.

The OMB is particularly interested in comments that will help:

1. Evaluate whether the proposed collection of information is necessary for the proper performance of the functions of the agency, including whether the information will have practical utility;
2. Evaluate the accuracy of the agency's estimate of the burden of the proposed collection of information, including the validity of the methodology and assumptions used;
3. Enhance the quality, utility, and clarity of the information to be collected;
4. Minimize the burden of the collection of information on those who are to respond, including through the use of appropriate automated, electronic, mechanical, or other technological collection techniques or other forms of information technology, e.g., permitting electronic submissions of responses; and
5. Assess information collection costs.

Proposed Project

The Muscular Dystrophy Surveillance, Tracking, and Research Network (MD STAR*net*) Muscular Dystrophy Questionnaire - New - National Center on Birth Defects and Developmental Disabilities (NCBDDD), Centers for Disease Control and Prevention (CDC).

Background and Brief Description

Since its establishment in 2002, the MD STAR*net* has been a population-based surveillance system that aims to identify and collect clinical data on individuals with muscular dystrophy (MD) in select surveillance areas. MD STAR*net* identifies and collects data on cases at sources, including healthcare facilities where patients with MD receive care and administrative datasets such as vital records and hospital discharge data. While MDs are rare genetic diseases with an estimated prevalence of 16.1/100,000, they have a high impact on affected individuals, their families, and society. MDs can be classified into nine major groups: Duchenne muscular dystrophy (DMD), Becker muscular dystrophy (BMD), myotonic dystrophy (DM), facioscapulohumeral muscular dystrophy (FSHD), limb-girdle muscular dystrophy (LGMD), congenital muscular dystrophy (CMD), Emery-Dreifuss muscular dystrophy (EDMD), and distal MD. A recent MD STAR*net* study has estimated the combined prevalence for DMD and BMD to be 1.92-2.48/10,000 males age 5-9 years old. MD STAR*net* aims to improve understanding of MDs and ultimately the quality of life of people and their families living with MD. Individuals with MDs frequently report pain and fatigue, but

studies have largely been conducted in clinic-based populations and included the three most common MDs. Population-based studies are needed to describe the frequency and management of pain and fatigue and their impact on the lives of individuals with various types of MD.

The purpose of the proposed study is to describe the epidemiology of COVID-19 and flu and the experience with pain, fatigue, pregnancy, and infertility for adults living with MD who are identified through MD STAR*net*. Results generated from the study will provide a better understanding of: 1) the occurrence, testing, treatment and severity of COVID-19 in relation to MD; 2) vaccination status and reasons for not receiving COVID-19 and flu vaccinations; 3) the frequency, intensity, and management of pain and fatigue; and 4) the effect of having MD on pregnancy and fertility on adults living with MD. Ultimately, this information can be used to develop interventions that improve the lives of people with MD and their families.

CDC requests OMB approval for an estimated 974 annual burden hours. There are no costs to respondents other than their time to participate.

Estimated Annualized Burden Hours

Type of Respondents	Form Name	No. of Respondents	No. of Responses per Respondent	Average Burden per Response (in hours)	Total Burden Hours
Adult males 18 and over	MD STAR*net* Male Questionnaire	1,794	1	15/60	449
Adult females 18 and over	MD STAR*net* Female Questionnaire	1,574	1	20/60	525
TOTAL					974

Jeffrey M. Zirger,

Lead,

Information Collection Review Office,

Office of Scientific Integrity,

Office of Science,

Centers for Disease Control and Prevention.

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